

**SELF-MANAGEMENT PLAN, PERCEIVED QUALITY OF LIFE
AND MEDICAL RESOURCE UTILIZATION OF ASTHMATIC CHILDREN**

By

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The impact of asthma self-management programs on medical resource utilization has been studied repeatedly. The impact of these programs on a child's perceived quality of life, however, has not been addressed. This descriptive, correlational study compared the perceived quality of life and number of hospitalizations, emergency room and clinic visits in asthmatic children ages 7 - 11 years who adhered to a self-management plan with those who did not adhere to a plan. Quality of life was measured using the Childhood Asthma Questionnaire, a valid and reliable quality of life measurement tool for children of different ages. There were no significant differences between the Adherence and Non-adherence groups relative to quality of life or medical resource utilization. Findings did support a significant decrease in medical resource utilization for both groups since the establishment of their self-management plan. These findings confirm the role of self-management education as a worthwhile and cost effective investment for children.

CHAPTER 1 INTRODUCTION

Asthma is a chronic disease that affects more than fourteen million persons, including 4.8 million (6.9%) children less than 18 years of age (CDC, May 3, 1996). The annual hospitalization rate for asthma among persons less than 24 years of age has increased 28% from 1980 to 1993 (CDC, May 3, 1996). A study by Weiss, Gergen and Hodgson (1992) estimated asthma-related costs at \$6.2 billion in 1990 in the United States. Inpatient hospital services represented the largest single expense averaging \$1.6 billion per year. Emergency room use required another \$90.4 million per year for pediatric patients alone.

In 1993, there were 5000 pediatric patients admitted to military treatment facilities in the United States resulting in an estimated cost of more than \$12 million. It has also been shown that hospitalization rates in military treatment facilities exceed national standards by 25% (Department of Defense, 1995).

In addition to these economic costs, there are psychosocial factors that affect the patient with asthma. For instance, asthma exacerbations, such as airway obstruction, inflammation, or increased airway responsiveness, may result in a child missing school, a parent missing work, or family activities being interrupted. The stigma of asthma may affect a child psychologically. A child may be teased by his peers when the disease limits physical activity. Teachers may treat asthmatic children differently than other children, or

they may be left out of certain physical activities. Military dependents with asthma may also impact the work of the active duty parent. The parent may not be able to function to fullest potential if the needs of the child are not being met. An asthmatic child whose asthma cannot be controlled may also limit the active duty parent's capacity to be stationed overseas where medical treatment facilities are not equipped to care for seriously ill children. All of these factors can have a serious impact on how the child views himself and his life.

Problem

In an attempt to address the growing numbers of asthmatic children and the far-reaching effects of the disease, health care providers have implemented self-management programs to increase knowledge and possibly control the disease. Self-management education "provides the patient with the educational experiences specifically designed to promote changes in behavior that will lead to an improvement in health status and ultimately enhance the quality of life" (Wilson-Pessano & McNabb, 1985, p.671).

Self-management programs aim to shift control of the disease from the health care provider to the child and their family. As parents and children learn more about asthma and how to intervene at the earliest sign of trouble, the goal is to decrease the number of emergency room visits and hospitalizations and keep the child in the home environment.

Although the self-management definition includes quality of life as a variable, few self-management programs explicitly define or measure quality of life. Instead, researchers generalize that quality of life is related to various self-management goals: 1) controlling symptoms; 2) decreasing interference with patient's activities; 3) reducing asthma's effect on the child's overall life; and 4) reducing family stress (including financial

stress) (Wilson-Pessano & Mellins, 1987). Quality of life is a new and important concept in outcomes research. Spilker, editor of the book Quality of Life Assessments in Clinical Trials, when addressing issues related to quality of life research, states one of the most important golden rules is "that only validated scales should be used in clinical studies" (1990, p. 8).

Purpose

This purpose of this study was to compare the perceived quality of life and the number of hospitalizations, emergency room visits and clinic visits in asthmatic children ages 7 to 11 years who adhered to a self-management plan and those who did not adhere to the plan.

Hypotheses

The hypotheses for this study were as follows:

- I. Children who adhere to an asthma self-management plan will have higher quality of life scores on the Childhood Asthma Questionnaire-Form B compared to asthmatic children who do not adhere to the self-management plan.
- II. Children who adhere to an asthma self-management plan will have a reduced number of emergency room visits, hospitalizations and clinic visits when compared to asthmatic children who do not adhere to the self-management plan.

Operational Definitions

A self-management program, for the purposes of this paper, is an individualized asthma control plan established based on criteria in the Guidelines for the Diagnosis and Management of Asthma developed by the National Heart, Lung and Blood Institute (1991). Based on peak expiratory flow rates, the reading from the peak flow meter, the

asthma control plan guides the child and/or the parent in the use of the medications, control of environment, when to call the health care provider, and when to seek immediate medical attention (National Heart, Lung and Blood Institute, 1991).

Adherence to the self-management plan was measured using the information gained from the Survey of Peak Flow Usage (see Appendix A). Adherence to the plan was determined by an "always" or "often" answer for question 2 (Do you use your peak flow monitor) and question 4 (Do you use your asthma control plan?) and a "5", "6", or "7" in answer to question 6 (How many days did you use your Peak Flow Monitor last week?).

Quality of life was measured using the Childhood Asthma Questionnaire-Form B (French & Christie, 1995). Quality of life scores rise with increased enjoyment of the activities in question. There is a separate questionnaire for each of these three age groups: CAQA for ages 4 - 7; CAQB for ages 8 - 11; and CAQC for ages 12 - 16.

Number of hospitalizations, the number of times a child was discharged from the hospital in which the primary diagnosis was asthma, was obtained through a chart review of the medical record. A "before" number was obtained by dividing the total number of hospitalizations by the number of months from first asthma symptoms to the Asthma Education Program. This "before" number was compared to an "after" number obtained by dividing the number of hospitalizations by the number of months from the Asthma Education to the chart review.

Number of emergency room visits, the number of times a child was discharged from the emergency department in which the primary diagnosis was asthma, was obtained through a chart review of the medical record. A "before" number was obtained by

dividing the number of emergency room visits by the number of months from first asthma symptoms to the Asthma Education Program. This "before" number was compared to an "after" number obtained by dividing the number of emergency room visits by the number of months from the Asthma Education to the chart review.

Number of clinic visits, the number of times a child visits the pediatric clinic in which the assessment by the health care provider is asthma related or the asthma control plan medication regimen is changed by the primary health care provider, was obtained through chart review. A "before" number obtained by dividing the number of clinic visits by the number of months from first asthma symptoms to the Asthma Education Program. The "before" number was compared to an "after" number obtained by dividing the number of clinic visits by the number of months from the Asthma Education Program to the chart review.

Significance

Many researchers have reported that asthma self-management plans have favorable outcomes related to resource utilization and financial costs. There are few studies that evaluate the effects of self-management plans on a child's perceived quality of life. Children's perceptions of their life as an asthmatic may affect not only their physical but their entire well being. This study attempted to show that helping the child to establish tight control of the asthma may reduce the number of hospitalizations and emergency visits, and provide children with a positive outlook of themselves as well as their lives. Children may gain a feeling of control over the asthma and thereby enhance their self-image.

With the population of the study being military dependents, and the number of hospitalizations for these dependents 25% higher than their civilian counterparts, this study has important implications for the military health care system. The active duty military member has a unique commitment to the job sometimes not seen in the civilian world. The military member's primary focus is duty to country. The military parent with a dependent asthmatic child may not be able to function to their fullest potential if their family's needs are not being met. An asthmatic child who is not well controlled may affect the promotion chances and utilization of the active duty member. A child with uncontrolled asthma will be restricted to several stateside medical treatment facilities and thus, limiting their parents' capacity to meet mission requirements. It is the primary goal of the military health care system to assist the family to achieve self-care and allow the military member to perform the job knowing their child's asthma is under control.

Another important implication is the possibility for conserving resources in a time when health care costs are escalating out of control. By controlling asthma symptoms with the use of self-management programs, the number of hospitalizations and emergency room visits may be decreased. The asthmatic child by using the asthma control plan is able to detect changes in the peak flow readings, possibly before symptoms are acute. By employing the guidelines (medications and environmental controls), an asthma attack may be stabilized before it has a chance to worsen. The child could be cared for on an outpatient basis and the need for hospitalization or an emergency room visit could be averted, thus saving money.

Information gained in this study may assist health care providers in helping asthmatic children manage developmental and emotional changes of normal childhood.

Findings from this study potentially may give children and their families incentives to develop self-management techniques to control this chronic disease.

CHAPTER 2

REVIEW OF LITERATURE

Asthma is a chronic disease that frequently affects children and may have physical, economic, and biopsychosocial implications. Self-management programs developed over the years have attempted to control asthma symptoms and provide positive outcomes. The Guidelines for the Diagnosis and Treatment of Asthma (National Heart, Lung and Blood Institute, 1991) have provided specific criteria for establishing asthma control plans for use in a self-management program. Adherence to these plans requires daily and rigorous effort, but may offer the child a feeling of control over asthma symptoms. The mastery gained from adherence to this plan may lead to feelings of self-efficacy, thus leading to a continued use of the asthma control plan. The relationship between adherence to a self-management plan or an asthma control plan and the child's quality of life is now being more closely studied. With this rise in quality of life research, several tools have been developed to measure the quality of life in asthmatic children. These tools will help health care providers evaluate various treatment plans not only on the basis of resource utilization or financial benefits, but also the impact on the life of the child.

Self-Efficacy

Self-management education is a basic premise in the treatment of asthma. An asthma control plan established for a child by the health care provider is a step by step guide for controlling asthma symptoms. The success of the plan however depends on its

utilization. The self-efficacy theory states that two expectations will influence a person's behavior: outcome and self-efficacy. Self-efficacy expectancy is the belief that the person can indeed perform the behavior needed to produce the outcome. Outcome expectancy is the belief that a behavior will lead to a certain outcome (Bandura, 1977). For example, adherence to the asthma control plan will occur if the child believes that the plan will improve quality of life and if the child feels competent to perform the peak flows monitoring necessary to make the plan a success.

The expectation of self-efficacy is based on four major sources of information: performance accomplishments, vicarious experience, verbal persuasion, and psychological states. Performance accomplishments are the most significant because they are based on personal successes performing the behavior, leading to positive reinforcement. If on the other hand, performance was unsuccessful, self-efficacy is most likely reduced. Vicarious experience is based on information received from others around them successfully performing the behavior. This information is less reliable because it relies on inferences from other's accomplishments. Verbal persuasion is the most widely used information source to influence to behavior. A person is lead by suggestion to believe they can perform a behavior. Emotional arousal stimulated by certain circumstances may influence how a person perceives a behavior or their ability to perform a behavior (Bandura, 1977).

Self-efficacy has a significant effect on behavioral change. As in the case of asthmatic children who utilize an asthma control plan, perceived self-efficacy could have an impact on the self-management outcome. If the asthmatic child is able to perform the tasks related to the asthma control plan (use of peak flow meters and medication administration) and is able to recognize potential quality of life changes, the desired

behavior may be elicited. That is if the child believes there is a favorable outcome, the daily routine may be tolerable, whereas, if there is no change the rigorous routine may not be worth it. It is the purpose of this study to compare the perceived quality of life in asthmatic children who closely adhere to a self-management program to those who do not follow the self-management program.

Asthma in Children

This study used the definition of asthma as a "lung disease with the following characteristics: (1) airway obstruction that is reversible (but not completely so in some patients) either spontaneously or with treatment; (2) airway inflammation; and (3) increased airway responsiveness to a variety of stimuli" (National Heart, Lung and Blood Institute, 1991, p.1). There are several differences in pediatric asthma as compared to adult asthma. First, the prevalence of asthma is "more common in children than in adults. Nearly one third of the asthmatics in the United states are children, and the number actually may be higher" (Harrington, 1991, p. 221). Underdiagnosis of asthma in children is common because of other diseases, such as bronchitis, croup, or pneumonia. These diseases may cause wheezing or coughing episodes, which are the primary symptoms of asthma. "For children, wheezing with respiratory infections is often asthma rather than wheezy bronchitis or pneumonia" (National Heart, Lung and Blood Institute, 1991, p. 1). According to the National Health Interview Survey results for 1982 - 1992, the prevalence of asthma increased 42% in the general population. The prevalence in those 5-34 years of age increased 52% during this same time frame (CDC, January 6, 1995). Although these increases may be related to health care providers making the diagnosis at an earlier time

based on the criteria instituted by the National Heart, Lung and Blood Institute, the implications are serious.

Another difference between the adult and the child are the anatomical differences. Narrower airways and decreased lung volume in children may lead to a quicker onset or a more severe asthma attack or exacerbation. Also, because of the child's cognitive and developmental level, their ability to express difficulties in breathing may possibly delay treatment in acute exacerbations, requiring rapid interventions to prevent decline in status.

Asthma also has psychological and psychosocial implications for children as well. Children are sometimes ostracized by their peers when they are not able to participate or keep up during exercise or sporting activities. Teachers and coaches may expect a child to do too much during physical education classes or organized sports, thinking that asthmatic children are faking symptoms in order to be excused from participation. Asthma attacks may postpone or cancel family activities, and the child bears the guilt of interfering with family plans. These instances may have a significant impact on how a child views their life and their disease. They may also influence how a child participates in the asthma treatment program, possibly providing an incentive for self efficacy. An incentive is the value of an outcome, and in this instance the outcome may be approval of others, improved peer relations, or a decrease in family tensions.

Children are also different from adults developmentally. Children are not simply "little adults." There are age-related differences in children that affect their whole being. "With increasing age, children strengthen and generalize their cognitive skills, increase their ego strength, imitate more accurately . . . process information more efficiently" (Kimball, Nelson & Politano, 1993, p. 27) and have a gradual increase in perceived

control (Skinner, 1992). It is imperative, therefore, that any interactions with children be on a developmentally appropriate level.

These differences make pediatric asthma a unique challenge for health care providers. Assisting patients and families gain control through adherence to a self-management plan and potentially attain some degree of reversibility of symptoms and chronicity of the condition needs additional study.

Economic Implications of Asthma

As noted previously, the prevalence of asthma is on the rise. Along with this rise, there is an increase in the morbidity associated with asthma. Morbidity is expressed in terms of emergency room visits and hospital admissions.

In a study of the economic impact of asthma in the United States, asthma-related costs were estimated at \$6.2 billion (Weiss, Gergen, & Hodgson, 1992). This number includes both indirect costs (patient and parental loss of work and absence from school) and direct costs (inpatient and outpatient hospital utilizations, emergency room visits, and medicines). The biggest percentage of the economic impact resulted from inpatient hospitalizations (\$1.6 billion). The use of emergency room services totaled \$200.3 million and almost half of the visits were for children under the age of 18. These data were based on information gathered during 1985, the costs were then estimated to reflect 1990 dollars, so, these numbers may presently be even higher.

Over the past 20 years there has been an impressive increase in the rate of hospitalizations in the pediatric population. Halfon and Newacheck (1986), using data gathered from the National Hospital Discharge Surveys, found a 145% increase from 1970 to 1984 in the rate of hospitalizations in children less than 15 years of age. From 1980 to

1993, the hospitalization rate for persons less than 24 years of age increased 28%, with the highest increase among children less than one year of age (35.6 to 64.7 per 10,000 population) (CDC, January 6, 1995). There are several possible causes for these increases beside the increasing severity of the disease. These other causes include changes in diagnostic criteria, classifying practices, changes in the environment (pollution, allergens) or an increased awareness of the disease (Evans, R. et al., 1987).

Military Influence

The Department of Defense (1995) recommended a study to measure current adherence to the National Heart, Lung, and Blood Institute's Guidelines in the Military Health Service System. This investigation consisted of a random chart review of 11 military treatment facilities across the US from September through December 1993, evaluating emergency and inpatient treatment of pediatric asthma patients. The findings from this study, published in May 1995, revealed that the incidence of hospital admissions for asthma in children eligible for care in the Military Health Service System is 25% higher than the national average (38.8 per 10,000 for military compared to 30.9 per 10,000 for national average). Although military dependents may have a higher incidence of asthma, the report indicates "that many admissions might have been avoided by closer adherence to the Guidelines for the Diagnosis and Treatment of Asthma (1991), especially in the areas of patient education and more aggressive ED [Emergency Department] management" (Department of Defense, 1995, p. iii).

The Department of Defense Consultants' conclusions and recommendations (1995) stated that, "for the vast majority of children, the morbidity and cost of hospitalization may be avoidable with more consistent patient education and follow-up" (p. ii). In accordance

with this recommendation, asthma education programs are being established in military medical treatment facilities across the country.

The active duty military member has a unique commitment to his/her job, that is not usually seen in the civilian world. The military member's primary focus is to the job as established by the government. The military parent who has a dependent child with asthma may not be able to function to their fullest potential if their family's needs are not being met. It is the goal of the military health care system to assist the family to achieve self-care and allow the military member to perform the job knowing their child's asthma is under control.

Another unique aspect in the military is the movement of personnel to overseas assignments. With the downsizing of the military there is an increased demand for jobs overseas. Health care overseas is limited, so military members with dependents whose asthma is poorly controlled are limited to state-side assignments, limiting their potential and possibly affecting their promotion opportunities. If the asthma can be controlled, the member may travel freely and increase their capacity. Controlling and possibly reversing symptoms, has a great impact on the mission of the active duty military members with asthmatic dependents.

Asthma Self-Management Education Programs

Self-management education for children with asthma was first developed in the 1970's. Self-management is any program that "provides the patient with educational experiences specifically designed to promote changes in behavior that will lead to an improvement in health status and ultimately enhance the quality of life." Self-

management's goal "include[s] increasing patient independence [self-care] rather than dependence on health-care providers" (Wilson-Pessano & McNabb, 1985, p. 671).

Over the past 20 years, many asthma self-management programs developed have shown favorable outcomes. These outcomes include a decrease in number of hospitalizations or emergency room visits (Alexander, Younger, Cohen & Crawford, 1988; Clark, Feldman, Evans, Wasilewski & Mellins, 1986; Greineder, Loane, & Parks, 1995; Lewis, Lewis, Leake, Monahan & Rachelefsky, 1996; Lewis, Rachelefsky, Lewis, de la Sota & Kaplan; and McNabb, Wilson-Pessano, Hughes & Scamagas, 1985), economic savings (Clark et al., 1986; Greineder et al., 1995; Lewis, Rachelefsky et al., 1984; McNabb et al., 1985), a decreased number of asthma attacks (Evans, D. et al., 1987 and Whitman, West, Brough & Welch, 1985), a reduction in number of school absences (Clark et al., 1986 and Kaplan et al., 1986) and an increase in knowledge and skills (Whitman, West, Brough, & Welch, 1985).

Many of these programs were evaluated and critiqued from many different angles. Howland, Bauchner, and Adair (1988) looked at thirteen studies related to self-management programs to assess their true impact on morbidity (school absences and health care utilization). They found that the effectiveness of the programs as a whole at reducing morbidity was small. They further recommended that patients, parents and health care providers should use these programs having "real expectations about what these programs accomplish" (p. 964). Although morbidity outcomes may not be large, there may be other outcomes that are more beneficial, such as an increase in "knowledge and psychologic well being of patients and their families" (p. 969). A meta-analysis of 11 research studies was completed by Bernard-Bonnin, Stachenko, Bonin, Charette and

Rousseau (1995). They concluded that these programs do not reduce morbidity (school absenteeism, hospitalizations, and emergency visits) and that future research should "focus more on intermediate outcomes such as behavior" (p. 34). Thoresen, and Kirmil-Gray (1983) assessed 11 programs and evaluated their relationship to self-efficacy of the asthmatic children. They found that 8 of the 11 programs "help the child and family develop a sense of self-efficacy regarding the ability to manage asthma" (p. 602). They concluded that a "program which included cognitive and analytic skills, careful daily assessment of pulmonary functioning...and efforts to build strong community support for the asthmatic child would optimize the likelihood skills taught would be learned and used and clinical outcomes improved" (p. 606).

The National Heart, Lung and Blood Institute's National Asthma Education Program issued Guidelines for the Diagnosis and Management of Asthma [Guidelines] in 1991. These Guidelines aid in the standardization of treatment of asthma by health care providers. It provides protocols and specific algorithms for the diagnosis, classification, and medical management of asthma in different populations and different situations. It also recognizes the role that education must have in the treatment plan in order to reverse the morbidity and economic trends. The Guidelines state the role of education involves "helping patients to understand asthma, learn and practice the skills necessary to manage asthma and be supported for adopting appropriate asthma management behaviors" (p.48). The Guidelines enable health care providers to develop individualized self-management programs for their specific population.

Treatment of Asthma

According to the Guidelines (1991) education needs to go beyond providing information, there must be a partnership between the provider and the child and family. The child and family must be included in all decision making regarding the management of asthma. The child and family must be aware of medication actions and side effects, use of inhalers, nebulizers, and peak flow meters and the role of environmental control. The child and family must be involved in the development of the asthma control plan, which is simply a step by step guide on how to treat one's asthma based on the use of daily peak flow meter measurements.

Medications

The medications used to manage asthma vary and depend on the health care provider's preferences or formulary choices. Most medications can be placed in two groups depending on their actions: bronchodilators or anti-inflammatory drugs. Bronchodilators, such as beta₂-agonists and theophylline, open airways by relaxing airway muscles. Anti-inflammatory medications, such as steroids and cromolyn, prevent and reduce inflammation (National Heart, Lung and Blood Institute, 1991).

Environmental Control

Any stimuli that can cause an asthma attack is a trigger. Identifying and removing triggers from a child's environment, may help reduce the number or severity of asthma attacks. Triggers can be allergens such as pollens or molds, irritants such as smoke, strong odors, or sprays, or physical conditions such as cold air or exercise. Some patients may be very sensitive to these triggers and may need to see an allergist for further work up (National Heart, Lung and Blood Institute, 1991).

Treatment Control Plan

This plan is an individualized guide that is set up by the health care provider, the child and family. The plan includes three ways to assist the child in gaining control over asthma. First, information is provided concerning specific medications, dosages and the instances when these medications are taken in accordance with peak expiratory flow rates. The traffic light approach is used: green (all clear), yellow (caution), and red (medical alert) to guide actions such as what medications to take and which symptoms are serious and need prompt attention. The second way the plan works is by offering reminders about avoiding triggers. The plan suggests that the child 1) stay indoors during times of high pollen counts, 2) avoid smoke and perfume, 3) reduce humidity in the home, and 4) stay away from people with a cold or flu. Thirdly, the plan lists all important information such as important phone numbers and reminders to see a healthcare provider regularly. Each health care provider involved in the development of asthma control plan needs an extensive background in the actions and uses of the various medications. They must also be sure to involve the child and family, follow the child's progress, and evaluate and change the plan as necessary.

Peak expiratory flow rates

Peak flow meters are devices that measure peak expiratory flow rates (PEFR), or the amount of air moving out of a patient's lungs. As the airways narrow, this PEFR will decrease most times before any other symptoms are noticeable. This peak flow meter is used as an objective measure to determine the severity of an asthma attack and how well a child is doing in relation to his personal best. There are no magic numbers, but rather zones: green, (80 - 100% of one's personal best PEFR), yellow, (50 - 80% of one's

personal best PEFR), and red, (less than 50% of one's personal best PEFR). One's personal best PEFR is the highest number achieved over a two week period when one is free of asthma symptoms. These zones are then paired with appropriate medications and dosages in the treatment control plan to guide the child in managing the asthma.

Peak flow meters may be used in children age 5 and over, who are able to perform the following steps: 1) stand up; 2) take a deep breath; 3) place meter in mouth and close lips around it; 4) blow out as hard and as fast as possible; 5) read the number from the meter. These steps are repeated and the best of three attempts is recorded. The peak flow should be performed two times each day (before medication in the morning and 10-12 hours later). During an exacerbation of asthma, peak flow meters may be used to determine the effects of medications by taking measurements before and after the use of certain medications.

Several researchers have reported that use of peak expiratory flow rates may be helpful in predicting asthma episodes (Harm, Kotses, & Creer, 1985 and Pinzone, Carlson, Kotses, & Creer, 1991) or detecting troublesome childhood cases (Linna, 1993). Peak flow monitoring has no ability to predict hospital admissions when used in the emergency department setting (Martin, Elenbaas, & Pingleton, 1982 and Yamamoto, et al., 1992).

In a study assessing who uses peak expiratory flow meters and the effect on how education on their usage influences usage, researchers examined 352 asthmatic patients, ages 7 to 55 years, attending an emergency room. Those owning a peak flow monitor at the beginning of the study(54%) had had asthma longer, sought care more often, and used more asthma medications. They found that only 16% performed daily peak flows at the beginning of the study, decreasing to 6% nine months later. The researchers concluded

that simply providing a peak flow monitor was not enough, consistent reinforcement over time was needed (Garrett, Fenwick, Taylor, Mitchell & Rea, 1994).

In a randomized controlled trial of 72 asthmatics (ages 15 to 40 years), where the only difference between the study group and the control group was the use of peak flow meters, the researchers found that peak flow measurements made no difference in lung function, symptoms, quality of life or prescribing costs (Jones et al., 1995). This study is unique in that it is one of the first to study the relationship between peak flow usage and quality of life in adult asthmatics. Although the study did not find any between-group differences using a quality of life tool developed for use with adult asthmatics, there was a significant ($p < 0.01$) improvement in all scores within the peak flow group from the beginning of the study to the end.

To summarize, peak expiratory flow rates used with an asthma control plan may be helpful in predicting attacks and may provide increases in perceived quality of life of daily users. Using this premise, this researcher compared perceived quality of life, number of hospitalizations, emergency visits, and clinic visits of asthmatic children who strictly follow a self management plan, and children who do not. By being able to predict an attack, the child may gain a feeling of control over the disease. This feeling of self-efficacy may provide the child with a more positive outlook on life and potentially an improved quality of life.

Military Self-Management Programs

After the release of the Department of Defense Consultants' recommendations (1995) to improve asthma education, asthma self-management programs are being established throughout the military health services system based on the Guidelines

(National Heart, Lung and Blood Institute, 1991). Naval Air Station, Jacksonville Florida (NAS-Jax) established an Asthma self-management program of its own in July 1995. With an asthmatic population of approximately 200 children, the pediatric clinic has begun asthma classes, taught by one of two pediatric nurse practitioners. When a patient is identified by either a health care provider, or the emergency department as having asthma, they are scheduled to attend a class to learn about asthma, including pathophysiology, medications, and environmental triggers. The children are then assigned a primary or continuity care provider to follow and care for them. If the child is over the age of 5 years and is determined by the health care provider to be at risk for continued asthma symptoms, they may be scheduled to attend another class to learn the use of peak flow meters and asthma control plans. The children continue to be followed by their continuity care provider and their asthma control plan is evaluated and updated as needed.

Quality of Life

Quality of life is a complex term and the definition usually depends on factors measured by the researcher in any particular study. In recent years, quality of life has been defined as "the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient" (Schipper, Clinch, & Powell, 1990, p. 16). For example if a treatment provides control over symptoms and provides little disruption of one's daily life compared to others not inflicted with the chronic disease, it is said to enhance quality of life. Quality of life is a multidimensional concept with four major domains: physical function; psychological state; social interaction; and somatic sensation (Schipper, Clinch, & Powell, 1990).

The self-efficacy model is closely related to quality of life. Perceived self-efficacy is the theory that health behaviors are influenced by a person's belief that the behavior can be successfully completed (self-efficacy expectancy) and that performing the behavior will lead to certain outcomes (outcome expectancy). As in the case of asthma self-management, a person will use an asthma control plan if one believes the plan will lead to control of asthma symptoms (outcome) and if one is able to successfully perform the peak flows (self-efficacy). Quality of life measures assess the impact of a self-management plan on a person's entire being. "Perceived self-efficacy in asthma management might be viewed as a quality of life outcome...[and] a possible predictor of self-management behavior" (Richards & Hemstreet, 1994, p. S31). Self-efficacy is then a piece of the quality of life concept, but the model may be used to explain the impact of self-management programs and their continued use by the asthmatic person.

Presently there are three questionnaires available for the study of quality of life in asthmatic children: The Pediatric Asthma Quality of Life Questionnaire (Juniper et al., 1995); Life Activities Questionnaire for Childhood Asthma (Creer et al., 1993), and the Childhood Asthma Questionnaires (French, Christie, & West, 1994). These tools are child-centered and disease-specific. They measure the impact of asthma on the various aspects of the child's everyday life.

The Pediatric Asthma Quality of Life Questionnaire consists of 23 items from three domains: symptoms, activity limitations, and emotional function. It is for use with asthmatic children ages 7 to 17 years (Juniper et al., 1995). The Life Activities Questionnaire for Childhood Asthma consists of 71 items dealing mainly with activity limitations (Creer et al., 1993). French, Christie and West (1994) have developed three

separate questionnaires for use in asthmatic children aged 4-7 years (CAQA), 8-11 years (CAQB), and 12-16 years (CAQC). CAQA requires parents to assist children in responding to picture stimuli and consists of two subscales: distress and quality of living. Distress is a measure of how the child feels about having asthma and having asthma symptoms. CAQB uses similar picture stimuli, but it is suitable for independent readers. This questionnaire reveals 4 subscales of distress, severity, active quality of life and passive quality of life. Distress here assesses unhappiness about having asthma, severity is the frequency of symptoms, active quality of life measures physically active times and passive quality of life measures sedentary pastimes. There is a section at the end of the CAQB for the parent to answer questions to provide feedback from a different perspective of the child's asthma. CAQC has 46 items and is a more advanced version of the same format. There are 5 subscales: distress, severity, reactivity (frequency of symptoms related to environmental triggers), active quality of life, and teenage quality of life (measures the extent of child involvement in social activities) (French & Christie, 1995).

The CAQ's assess each of the three age groups using an age-specific and developmentally appropriate format. Juniper's questionnaire and Creer's questionnaire both use the same questionnaire across the age spectrum. "The quality of the data we collect may vary depending on the age and cognitive capacity of the child" (Johnson, 1991, p. 367). By providing three questionnaires, Christie and French have addressed these developmental differences. "Given...the need to span the age range from toddlers to teens, it must be evident that the 'moving target' requires modifications of approach to questionnaire development, in order to communicate effectively with children of differing ages" (French et al., 1994, p.157). According to French and Christie (1995), the age

limits are suggestions and are flexible as determined by the researcher. The population assessed in this study was children ages 7 to 11. This age group enabled the researcher to increase the sample size. The CAQB was used for the study.

Instrument Validity and Reliability

The Childhood Asthma Questionnaires were developed by a team of researchers having extensive experience in psychometric assessment, children's attitudes and feelings, chronic disease management and asthma. All three questionnaires have been tested in some degree for reliability and validity. The validity and reliability of the CAQB will be discussed here.

Content Validity

The authors of the CAQB used a review of literature and feedback from a workshop of health professionals who were experts in educational and developmental psychology and psychometrics in the development process. One recommendation from this workshop was the need for different versions appropriate to several age ranges. Discussion groups with school children, some with asthma and some healthy, were used to develop appropriate questions as well as assessment techniques, such as the blocks for quantity and "smiley" faces for feelings that are used in the questionnaire.

Construct Validity

Comparing scores of asthmatic and nonasthmatic children, the asthmatic group participated in passive activities (playing with toys, reading, watching TV) more often than nonasthmatic children and feel happier when doing so. Asthmatic children go swimming more often but enjoy it less than nonasthmatic children. Nonasthmatic children also enjoy running around at playtime more than asthmatic children. (French et al., 1994). These

findings indicate that children feel differently about active and passive pastimes, and they should be regarded differently. For this reason, the CAQB differentiates between active and passive quality of life.

The first factor analysis performed, identified several factors: frequency of daily activities; feelings about asthma; feelings about physical activities; and frequency of symptoms. The "feeling" items had higher commonalities than the frequency items. This point may be due to the format of the questionnaire or the fact that children have little control over how often they are able to do certain activities. Therefore, the quality of life subscales count only the "feeling" items and not the "frequency" items. The format remained the same and "frequency" items are used to provide an orientation for each new question (French et al., 1994).

A further factor analysis identified four factors: severity (SEV), passive quality of life (PQOL), distress (DIS), and active quality of life (AQOL). It was notable that the factor analysis identified the same findings as the comparison of asthmatic and nonasthmatic children with the passive and active quality of life. SEV and AQOL were negatively correlated ($r = -0.37$, $p < 0.001$) and level of DIS was more strongly related to AQOL than to SEV ($r = -0.36$, $p < 0.001$ and $r = 0.24$, $p < 0.001$ respectively). A multiple regression analysis showed DIS and SEV were independent predictors of AQOL. This finding emphasizes the idea that health-related quality of life is a subjective measure related more to how a child felt about the disease rather than to how symptomatic they were (French et al., 1994).

Test-Retest Reliability

The CAQB has been found to have stability of scores over a three week period when tested with two separate samples, see Table 1. The reliability coefficients range from 0.70 to 0.75 in both samples.

Table 1

<u>Test-Retest Reliability for Sample of Asthmatic and Healthy Children, Ages 8-11 years</u>		
3 Week Interval	103 Asthmatic Children (mean age 9.8 years)	153 Healthy Children (mean age 9.5 years)
DIS	0.75	
SEV	0.73	
AQOL	0.74	0.74
PQOL	0.75	0.70

Note. The values represent the reliability coefficients between the two sets of scores. (French & Christie, 1995, p. 18).

Internal Consistency

The CAQB has been assessed for internal consistency in two separate samples, and has been found to be a reliable instrument of quality of life in children with Cronbach alpha values ranging from 0.21 and 0.44 for Passive Quality of Life to 0.82 in the Distress Subscale, see Table 2. The low PQOL values suggest that passive quality of life may indicate individual differences in broad terms and not specifically health-related quality of life. (French et al., 1994).

Table 2

Internal Consistency Testing for Asthmatic and Healthy Children, Ages 8 - 11 years

	103 Children with Asthma (mean age 9.8 years)	153 Healthy Children (mean age 9.5 years)
DIS	0.82	
SEV	0.77	
AQOL	0.66	0.69
PQOL	0.44	0.21

Note. Values represent Cronbach's alpha. (French & Christie, 1995, p. 17).

The Childhood Asthma Questionnaire, Form B was the instrument used in this study. The three CAQ's have been used in clinical drug trials to assess the quality of life related to various medication regimes. Dr. French states that the impact of treatments such as educational programmes or changes in the organization of care are [also]... suitable areas for their use (French & Christie, 1995, p. 3). The questionnaire may also be used to evaluate the biopsychosocial aspects which determine patients' responses to the challenge of self-care management of asthma (French et al., 1994, p. 178). One disadvantage with using the CAQ is that one age group may not be compared to another, meaning that a large enough sample of each age group will be needed in order to show a statistically significant correlation. For this reason, the researcher chose to study one age group, asthmatic children ages 7 - 11 years.

Resource Utilization

Quality of life is a subjective measurement and some children may adapt more easily to certain conditions or symptoms than others. Christie and French (1995) do not

recommend the CAQ be used alone to make between-subject comparisons. For this reason, this author measured other characteristics related to self-management and may have impacted a child's perceived quality of life. These include frequency of hospitalizations, emergency department visits, clinic visits related to asthma. These measures were used to compare and better describe the sample population.

This study incorporated a chart review of each child's medical record to record the number of hospitalizations, emergency visits, and clinic visits at the pediatric clinic related to asthma. These variables were compared between the children who adhered to the self-management plan (Adherence group) and the children who did not adhere to the self-management plan (Nonadherence group). The variables were also compared for differences before and after implementation of the self-management plan.

Healthy people 2000: National Health Promotion and Disease Prevention Objectives (Public Health Service, 1991) identify three specific objectives related to asthma. These objectives include decreasing hospitalizations for asthma in children under the age of 14 years (Objective 11.1), reducing activity limitation related to asthma (Objective 17.4), and increasing asthma education (Objective 17.14).

Hospitalization for asthma is usually viewed as a negative aspect for the patient and family. Using the asthma control plan and the step-wise organization, it is the ideal that the child never reach the "red zone". But there will be times when no matter what the child does, an asthma exacerbation may not have the possibility to be controlled as an outpatient. In these patients who have extreme tightness and difficulty breathing, the hospital may actually be seen as a good thing. They are now surrounded by knowledgeable and compassionate people who want only to make them breath easier.

The parents too may feel a sense of relief that their child is well cared for and will receive a similar sense of relief as easy breathing returns.

Emergency visits are also usually viewed as a negative variable, especially if the child is discharged in a relatively short time. For the same reasons listed above regarding hospitalizations, emergency room visits may be a relief for the child and family. Emergency room care is considered a negative variable because of its enormous expense. The cost of emergency care for children with asthma less than 17 years of age in 1985 was \$90 million, nearly one half the cost for the entire population (Weiss, Gergen & Hodgson, 1992). If children can be treated as outpatients, the resulting financial savings are considerable. A study examining the effects of an Asthma Outreach Program, found that by decreasing emergency room visits 79%, and hospital admissions 86%, their program saved \$8 for each \$1 their program spent (Greineder, Loane & Parks, 1995). Although this was a pilot study, the financial benefits were impressive.

Asthma exacerbations may occur for many different reasons. Even though asthma attacks may quickly worsen, they are usually preceded by some early warning signs or symptoms like sore throat, cough or decrease in peak flow reading. The asthma control plan is based on the premise that asthmatics can learn to recognize these early warning signals and intervene with the appropriate medication to stop the attack before it worsens.

Methodology

This study is a descriptive study which compared asthmatic children ages 7 to 11 years involvement in an asthma self-management program. Children were compared on a continuum with children who adhere to the program (Adherence group) on one end and with children who do not adhere to the self-management program (Non-adherence group)

at the other end. These groups were compared to each other on their perceived quality of life, and resource utilization (number of hospitalizations, emergency room visits, and clinic visits). Another piece of the study looked at each group (Adherence group and Non-adherence group) over time and compared resource utilization before the asthma Education Program and after the Program.

Design

Correlational research identifies a relationship or association between two variables when the researcher does not control the independent variable. In this study, the asthmatic children have already completed the asthma classes to learn about peak flows and asthma control plans. The researcher compared the asthmatic children based on adherence to the asthma control plan, to determine if those using the asthma control plan as directed (daily) had an increased quality of life and fewer hospitalizations, emergency room visits, and clinic visits than those who did not adhere to the plan.

In order to better compare the two groups, the researcher used the ex post facto design to compare the groups before and after interaction with the independent variable. Through chart review, the number of hospitalizations, emergency room visits, and clinic visits before the program were compared with the same since the program's inception.

Although ex post facto and correlational designs are considered weak for their ability to establish causal relationships, they do offer some advantages over other designs in studying this population. Because quality of life has not been studied as an outcome of self-management programs, this type of design provides information describing a potential relationship. These designs may be used to determine a directional causal relationship. A directional causal relationship states that a change in one variable will likely show a change

in another. For example adhering to a self-management plan may lead to a higher quality of life score as compared to not adhering to a self-management plan. Disadvantages for this type of design, include no random selection of groups and no manipulation of independent variable by the researcher (Polit & Hungler, 1995).

Sample

The sample for this study consisted of all available asthmatic children ages 7 to 11 years who have completed a Peak Flow Asthma Class and includes information from the Guidelines (1991) about peak flow usage and asthma control plans. The Peak Flow Asthma Class is the second of two classes within the Asthma Education Program. The first class is an Asthma Basics class. Both classes are offered two times each month and instruction is by one of two pediatric nurse practitioners. The children attended the class with a parent(s) and all were instructed on the correct way to perform peak flows with practice time and return demonstration provided.

In the classes, the children and parents learned how to use their asthma control plans. After the class the child was referred back to the primary care provider for help in individualizing and evaluating the effectiveness of the asthma control plan.

The sample consisted of dependent children of active duty or retired military members who attended the Asthma Education Program at the Pediatric Clinic at NAS-Jacksonville. Approximately twenty-five hundred children visit the pediatric clinic each month, approximately two hundred children with asthma are registered at the clinic. The number of children who were available for the study was small due to the constant movement of military personnel and the introduction of Tricare, a military HMO, which allows military members to choose civilian physicians as their primary health care provider.

Approximately 125 children have completed the Asthma Education Program based on the Guidelines (1991) since its inception in July, 1995. The number of children, between the ages of 7 and 11, who attended the Asthma Education Program and who used the Pediatric Clinic at NAS Jacksonville was 24 children. The ages of the children for the study were between the ages of 7 and 11 years of age to correspond fairly closely to the ages of the CAQ-Form B (ages 8 to 11 years). French and Christie (1995) state that the age limits are simply suggestions and are flexible as determined by the researcher.

Implications

If through adherence to a self-management program, the asthmatic child can gain a feeling of self-efficacy and in turn can have a more positive outlook, quality of life (an outcome expectation) may be enhanced. Asthma may be triggered by psychological triggers including anxiety and fear. If a child were to have a more positive quality of life, he may be able to prevent those asthma attacks (self-efficacy expectation) brought on by these psychological triggers. Additionally, the plan empowers them to take control of this disease and feel good about doing so, it will not only have physical and psychological implications, but potential economical implications as well.

This study compared each child's use of medical resources before and after starting the self-management plan. With the adherence to a self-management plan a child may be more aware of the symptoms of asthma and may be able to initiate early interventions. These early interventions may in turn reduce the utilization of the emergency room as a primary care provider and empower the child and the family to treat the symptoms using the asthma control plan. Hospital admissions may be decreased as well as more children are able to manage the symptoms on an outpatient basis. The number of clinic visits for

asthma may however increase because the children are seen on a regular basis to assess their status. Also children may see the primary care provider at an earlier point in time ("yellow zone") instead of waiting until reaching the "red zone" or the point of a medical emergency requiring an emergency room visit..

To summarize, this research looked at the impact of a self-management program on an asthmatic child's perceived quality of life as well as medical resource utilization. It postulated a relationship between adherence to a self-management program and a child's perceived view of self and the disease as it influences daily living. It also postulated a decrease in resource utilization after establishment of an asthma self-management program.

The information gained from this study may potentially give a health care provider the needed insight into how asthmatic children view themselves in relation to their asthma. In gaining this knowledge, providers may be better equipped to teach self-management techniques to asthmatic children, by enabling them to improve their quality of life and self-efficacy.

CHAPTER 3 METHODOLOGY

This study compared the perceived quality of life and the number of hospitalizations, emergency room visits, and clinic visits in asthmatic subjects ages 7 to 11 years who adhered to a self-management plan and those who did not adhere to the plan. It provided an opportunity to measure how children can affect their asthmatic condition while at the same time measured how their asthmatic condition may affect the quality of their own lives.

Design

This was a descriptive ex post facto, correlational study of asthmatic subjects ages 7 to 11 years at a military base in the United States. The independent variable was the utilization of an asthma self-management plan. Each of the subjects attended a Peak Flow Asthma Class and had an asthma control plan established for them. These plans assist them in recognizing symptoms and knowing how to treat their asthma. Although it is individualized to the subject, all control plans contained the same information:

1. Medication dosage, frequency, adverse effects to report and guidelines to change or add medicines if appropriate.
2. Usage of PEFR for monitoring airway obstruction as early as possible.
3. Criteria for initiating or modifying treatment, for example a decrease in PEFR or other symptoms.

4. Steps to follow to treat acute attack for example remove irritants, medications, rest, and remaining calm.
5. Criteria to seek emergency medical care.

The dependent variables were the subject's perceived quality of life and number of hospitalizations, emergency room visits, and clinic visits for asthma. The Childhood Asthma Questionnaire Form B (CAQB) is a developmentally appropriate, disease-specific tool that measures each subjects quality of life. The CAQB measured distress (unhappiness about having asthma), severity (frequency of symptoms), active quality of life (how one feels while involved in physical activity), and passive quality of life (how one feels while involved in quiet activities) (French & Christie, 1995). Number of hospitalizations, emergency room visits, and clinic visits were recorded through chart review.

Confounding variables in this study include the subject's variation of plan relative to their primary care provider, their asthma classification (moderate or severe), and their parent's involvement in their program. These variables were controlled for by identification through chart review, a Survey of Peak Flow Usage (see Appendix A), and the parent section at the end of the CAQB. Because this was a one time measurement of quality of life in the asthmatic subject, there were several extraneous variables that directly affected quality of life and exacerbations of asthma. Examples of potential variables included stresses felt by the subject (family or peer problems), cold symptoms, allergen influences or weather.

Setting

The study used the asthmatic population at the Pediatric Clinic at Naval Air Station, Jacksonville, FL. Approximately twenty five hundred children visit the pediatric clinic each month and approximately two hundred with asthma were registered at the clinic at the time of the study. However the numbers were small due to the continuous movement of military personnel and the introduction of Tricare, a military HMO. Tricare allows military members to choose a civilian physician as their primary health care provider. Approximately 125 subjects have completed the Asthma Education Program based on the Guidelines (1991) since its inception in July 1995.

Sample

The number of subjects, between the ages of 7 and 11, who attended the Asthma Education Program and who used the Pediatric Clinic at NAS Jacksonville as their primary health care provider was 24 children. The inclusion criteria for the study included:

1. Ages 7 - 11 years who attended an Asthma Education Program.
2. An asthma control plan individualized by primary health care provider established.
3. Willingness to complete peak flow survey form and CAQB.

Of the 24 possible subjects, the researcher was unable to contact 2 possible subjects due to wrong or disconnected phone numbers. One possible subject was out of state and not due to return until June. Seven possible subjects did not agree to participate. The final sample size consisted of 14 subjects fitting the above inclusion criteria.

Procedure for Data Collection

The sample population was identified by health care providers as having completed the Asthma Education Program. The families were contacted by the researcher and asked to participate in the study. The subject and parent(s) were asked to come either to the pediatric clinic, or a home visit was arranged. During this first contact, the study was explained, all questions were answered, and the parents and subject signed the consent form (see Appendix C). A Survey of Peak Flow Usage (Appendix A) was completed by the subject to help determine peak flow use, to help describe the sample and to identify possible confounding variables.

After the survey form was completed, the subjects were asked to complete a CAQB. The CAQB is one of a group of three questionnaires that was developed for a specific age group (ages 7 to 11 years) and has been tested to be a reliable and valid measure of perceived quality of life of asthmatic children (French & Christie, 1995).

The subject's medical record was reviewed. The information contained on the Demographic Survey (see Appendix B) was retrieved from the record including the number of hospitalizations, emergency room visits, number of clinic visits related to asthma and demographic data to better to describe the sample. The subject was given an identification number that was used as the identifier and all information was kept secure and confidential.

Procedure for Protection of Subjects

A consent form was obtained from the parent(s) and subject for permission to enter into the study (see Appendix C). The benefits and risks for the study were identified. All information gained from the study was held secure and confidential. The

study was approved by The Institutional Review Board at the University of Florida and by the Director of the Committee for the Protection of Human Subjects at the Hospital at NAS Jacksonville.

Summary

This research aimed to compare two groups of children (ages 7 to 11), those who adhere to a self-management plan and those who do not adhere. Adherence was based on replies from the Peak Flow Usage Survey. These two groups were then compared on their use of medical resources such as hospital admissions, emergency room visits, and clinic visits both before and after the Asthma Education Program. This data was obtained from a chart review of their record available through the Naval Air Station, Jacksonville. The two groups were also compared on their Quality of Life Scores, obtained from a valid and reliable measurement tool: the Childhood Asthma Questionnaire-Form B (French and Christie, 1995). It was hypothesized that those children who adhered would use less medical resources and have a higher Quality of Life score. The next chapter will discuss research findings and statistical analysis of the data.

CHAPTER 4 RESULTS

This study was conducted to compare the perceived quality of life in asthmatic children to adherence to a self-management plan. Adherence was determined using the subject's answers to the Survey of Peak Flow Usage (Appendix A). The Adherence and Non-adherence groups were also compared in their use of medical resources such as hospital admissions, emergency room visits and clinic visits.

Sample Description

Subjects were identified from the possible 24 subjects ages 7 to 11 who had attended the Asthma Education Program and had an individualized asthma control plan. All 14 subjects and their parents who agreed to participate completed the required Survey of Peak Flow Usage and Childhood Asthma Questionnaire-Form B (CAQB).

Table 3 describes the demographic characteristics of the subjects. The mean age of the subjects was 8 years 7 months with the oldest being 11 years 4 months and the youngest 7 years 5 months. There was no significant difference in the listed demographic characteristics between the five subjects in the Adherence Group and the nine subjects in the Non-adherence Group.

Scoring the Childhood Asthma Questionnaire

The four subscales within the Childhood Asthma Questionnaire-Form B (CAQB) are Active Quality of Life (AQOL), Passive Quality of Life (PQOL), Distress (DIS), and Severity (SEV). AQOL scores, which measure how a child feels about active

Table 3

<u>Demographic Characteristics of Sample (n=14)</u>		
Characteristic	Frequency	Percent
Age		
7 years	2	14.3
8 years	5	35.7
9 years	4	28.6
10 years	1	7.1
11 years	2	14.3
Gender		
Male	7	50
Female	7	50
Race		
Asian	4	28.6
Black	2	14.3
White	8	57.1
Group		
Adherence	5	35.7
Non-adherence	9	64.3

behaviors, such as running, swimming, and playing, ranged from 7 (low) to 35 (high).

PQOL scores, which measure how a child feels about passive behaviors such as reading, drawing and watching television, ranged from 4 (low) to 20 (high). Statistical analysis

revealed that PQOL was unrelated to DIS and SEV, suggesting that PQOL is not a health related quality of life, and therefore, not related to asthma symptoms (French, Christie, & West, 1994). The DIS scores, which assess how unhappy a child feels about asthma, ranged from 6 (low) and 30 (high). The SEV scores, which measure frequency of asthma symptoms, ranged from 6 (low) to 23 (high). DIS and SEV are independent predictors of AQOL, as indicated by statistical analysis, and it is suggested the between group differences of two or three points are clinically meaningful (French & Christie, 1995).

Data Analysis Procedures

This study examined two hypotheses. The first hypothesis compared adherence to a self-management plan and Quality of Life Scores. Because the sample size was small and demographically similar and the quality of life scores were ranked from high to low, the researcher chose to use the Wilcoxon Sum Rank Test for data analysis. The Wilcoxon test is a nonparametric statistical test used to examine the differences between the mean ranks of two groups.

The second hypothesis compared resource utilization such as hospitalizations, emergency room visits and clinic visits before and after the Asthma Education Program between the Adherence and Non-adherence groups. The t-test for independent samples was used to compare data from both groups. A t-test is a parametric statistic that analyzes the difference between the means of two samples. The t-test allows the researcher to conclude if the differences are significant (rejecting the null hypothesis) and the probability that the difference may have happened by chance. Independent samples assumes that the data were obtained from different subjects in two separate groups and the data from the two groups were not related.

Hypothesis I

The hypothesis that children who adhere to an asthma self-management plan will have higher quality of life scores compared to those children who do not adhere was not supported by these data. The specific means, standard deviations, and p-values using Wilcoxon Scores are stated in Table 4. The Quality of Life scores were relatively close in all subscales for both groups. The largest differences found in PQOL (1.7 points) and SEV (1.4 points). There was also a considerable but consistent variability in responses within the subjects as demonstrated by the standard deviations.

Table 4

Comparison of Adherence and Non-adherence Groups with Quality of Life Subscales

Subscale	Adherence Group		P-values	
	(n=5)			
	Mean/	Standard Deviations		
DIS	24.4 / 3.54	24.4 / 3.58	0.7877	
SEV	12.4 / 3.13	11.0 / 3.61	0.5012	
AQOL	29.2 / 5.40	28.8 / 4.84	0.9466	
PQOL	19.0 / 1.73	17.3 / 2.78	0.1921	

The CAQB has been used to measure quality of life with six other samples including non asthmatic children, mild or symptom free asthmatics and moderate/severe asthmatics. Comparable mean scores include 27.25 for AQOL, 24.55 for DIS, and 14.34

for SEV in the samples that include the mild to severe asthmatic groups and the mean AQOL was 28.62 for the asymptomatic or nonasthmatic children. In relating these numbers with the results from this study, the AQOL scores from both groups in this study were higher than those in all of the comparison groups above. The DIS scores were similar among all groups, and the SEV scores were lower in this sample with a greater than three point difference between the comparison mean and those in the Non-adherence Group.

Hypothesis II

The hypothesis that children who adhered to a self-management plan will have a reduction in medical resource utilization when compared to children who did not adhere to the plan was not supported by these data. There was a significant difference in the months after the Asthma Education Program with the Adherence Group averaging only 6 months since the Program and the Non-adherence Group averaging 11.2 months since the Program ($t = 2.219$, $p = 0.0465$). See Table 5 for a complete synopsis of the values.

Asthma is known to have seasonal variations in both hospitalizations and mortality in the United States with children tending to have more hospitalizations in September through November (Weiss, 1990). In order to better represent the findings in light these seasonal variations, data about resource utilization were compared on an episodes per subject per month basis rather than the actual numbers. The Adherence Group had an increased percentage of clinic visits (0.45 visits per subject per month) as compared with the Non-adherence Group (0.22 visits per subject per month).

Table 5

Comparison of Adherence and Non-adherence Group and Medical Resource Utilization Before and After Asthma Education Program

		Adherence		Non-Adherence		P-
		(n = 5)		(n = 9)		values
		Total Numbers (n)	Mean (Standard Deviation)	Total Numbers (n)	Mean (Standard Deviation)	
Before (months)			66.60 (26.23)		66.44 (17.65)	0.9896
--Hospitalizations	2		0.005* (0.006)	13	0.02* (0.008)	0.0794
--ER Visits	9		0.02* (0.02)	26	0.05* (0.04)	0.2030
--Clinic Visits	129		0.37* (0.28)	127	0.23* (0.21)	0.2778
After (months)			6.00 (5.15)		11.22 (3.67)	0.0465
--Hospitalizations	0		0* (0)	0	0* (0)	
--ER Visits	0		0* (0)	0	0* (0)	
--Clinic Visits	14		0.45* (0.22)	23	0.22* (0.18)	0.0591

Note: *Values are expressed as episodes per month per subject.

Given that difference in clinic visits, there was a significant decrease for emergency room usage ($t = 3.381, p = 0.0049$) and hospital admissions ($t = 2.785, p = 0.0155$) for the total sample. Since participation in the Asthma Education Program, subjects in both the Adherence and Non-adherence groups as a whole had no emergency room visits or hospital admissions.

Summary

The two hypotheses postulated by the researcher were not supported. The perceived Quality of Life and the utilization of medical resources were not statistically different between two groups of asthmatic children who differ in their adherence to a self-management plan. The Asthma Education Program that all children attended to receive their self-management plan however did make a difference in medical resource utilization with a statistically significant decrease in emergency room visits and hospital admissions after the program.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

The purpose of this study was to compare the perceived quality of life and medical resource utilization of asthmatic children and adherence to a self-management plan. The National Heart, Lung and Blood Institute issued the Guidelines (1991) to assist the health care provider, the patient and the family manage and control asthma symptoms. It encourages the patient to perform peak flow monitoring on a daily basis, keep track of these numbers, and correlate the numbers with “green,” “yellow,” and “red” zones of the asthma control plan. The asthma control plan then assists the patient and family to know what medications are needed and if further treatment is necessary. The main premise of this strategy is use of the asthma control plan on a daily basis, will improve control over asthma symptoms, possibly avoiding more serious consequences, such as emergency room visits or hospital admissions.

It was this idea that provoked this researcher to study the effects of adherence to the self-management plan, including peak flow monitoring and asthma control plans, on outcomes such as quality of life and medical resource utilization. There were no statistically significant differences between the adherence sample and the non-adherence sample. However, the group as a whole (Adherence and Non-adherence Groups) had a statistically significant decrease in the number of emergency room visits and hospitalizations after the Asthma Education Program.

Conclusions

The Asthma Education Program, utilized by children in this study is based on the National Heart, Lung and Blood Institute's Guidelines (1991) and was effective in decreasing hospital admissions and emergency room usage. The entire sample of this study attended the Program to learn about peak flow monitors and asthma control plans. Since completion of this program none of the children has been admitted to either the hospital or the emergency room at NAS Jacksonville. The data demonstrate the effectiveness and efficiency of this program. The asthma control plan allows the child and family begin medications, especially steroids, at the first sign of asthma symptoms. A confounding variable that may be responsible for this decrease in medical resource utilization, may be the early introduction of the steroids, resolving symptoms which may in turn lead to a positive outcome and increased self-efficacy.

The Program is presented two times each month by a pediatric nurse practitioner, it consists of 2 classes each lasting approximately one hour, and uses only minimal resources. Weighing this cost against the 100% decrease in hospital admissions and emergency room visits, the economic benefit is quite evident.

Another important finding was the significant difference in the number of months since the Asthma Education Program between the Adherence and Non-adherence Groups. The Adherence Group's mean time since attending the Program was only 6 months, whereas the Non-adherence Group's mean time was 11.2 months. This result may indicate that the Adherence Group still has the information fresh in their minds while the Non-adherence group have forgotten the information, or find it not worth the effort, or have lost interest in the self-management plan. On the other hand, it may indicate that the

Asthma Education Program has improved over time and has a stronger impact on the children and their parents leading to an increased adherence to the plan.

There was a difference, although not statistically significant, in the number of clinic visits after the Asthma Education Program, with the Adherence Group 0.45 mean visits per child per month and the Non-adherence Group 0.22 mean visits per child per month. The self-management plan includes monthly or every other month check-up visits with a healthcare provider to assess symptoms, medications and the control plan. Although this difference may indicate that the Adherence Group are more ill requiring more clinic visits than the Non-adherence group, this does not seem to be the case since none of the children from the Adherence Group were admitted to the emergency department or the hospital during the study period.

Another important finding is quality of life scores were similar for both Adherence and Non-adherence Groups. There are several explanations for this finding. First, quality of life is difficult to assess during one visit because of the many things that can impact a child's quality of life on any given day. To illustrate how quality of life is a subjective notion, I recall one child surveyed during a home visit. He was called to the kitchen table by his mom and arrived slightly short of breath and audibly wheezing. After several moments introducing the study and the procedures, he proceeded to complete his survey and CAQB. Review of his CAQB revealed that he had been wheezing a lot recently and was very unhappy when he was wheezing, but he also answered he had not had an asthma attack recently, that his asthma had not been too bad recently and that he was very happy about having asthma. Information gained from his parent revealed a mild severity that was very well controlled. This provides an example of the relativity of the quality of life

concept. A child may wheeze often and feel bad when he wheezes, but does not always realize that he is wheezing. The wheezing heard by the researcher may have been normal breathing for this child, but an asthma exacerbation for someone else.

Secondly, the children in the population were classified by the clinic providers as moderate to severe asthmatics. The health care providers only recommended the Peak Flow Monitoring portion (the second class) for those children who had been admitted to the hospital or emergency room, or a child a health care provider identified as a risk for further problems. It is possible that some of the children identified in the study were not severe or moderate, but rather mild asthmatics. French & Christie (1995) state that asthmatic children not exhibiting symptoms and non asthmatic children do not significantly differ in their quality of life scores. So if these children were indeed "mild" asthmatics or not exhibiting symptoms, a difference in quality of life scores would not be expected. To further explore this idea, question 22 of the CAQB asked the child how their asthma has been recently, 86 % answered "not too bad". Question 3 asks the parent to rate the severity of their child's asthma and 79 % answered "mild". There was also a high degree of agreement between the parent and the child regarding severity with only 14% disagreeing about the severity of the asthma.

To summarize, this research raised many important questions for future research. Findings from this study support the Asthma Education Program as an effective method for decreasing medical resource utilization mainly emergency room visits and hospital admissions, thereby saving time and money for the health care organization as well as the child and family.

Strengths, Weaknesses and Limitations of the Study

Even though the hypotheses were not supported, there were several significant strengths in this research. One strength of the study was the use of the Childhood Asthma Questionnaire-Form B (CAQB), a reliable and valid tool for studying quality of life outcomes in asthmatic children ages 7 to 11. The children had no trouble completing the questionnaire and most found it easy to understand. A few of the younger children actually enjoyed coloring the “smiley” faces and blocks different colors. The developmentally-appropriate format and encompassing questions provided an abundant amount of insightful details on how children feel about having asthma, and how the disease effects their daily lives.

Another strength of the study was the direct focus on measuring children perceptions of their asthma. The CAQB is a child centered, developmentally appropriate tool, enabling the researcher to appreciate the children’s perceptions of their world. This was difficult at the beginning of the session, but eased as the child proceeded with the survey and questionnaire. For example, at the beginning of the CAQB, the children looked to the parent for the answers, but when the parents, as instructed, did not offer any assistance, the children proceeded to answer the questionnaire by themselves with little difficulty. The researcher emphasized the importance of how they felt about asthma and not whether there was a right or wrong answer to the question.

The research study had several weaknesses in design. One weakness of the study was the small sample size. Because the CAQ has three age-specific forms, it was difficult to obtain the numbers needed to show a statistically significant difference. Although one study using the CAQs found a significant treatment effect with a sample of just 21

children, French & Christie (1995) recommend large sample sizes of more than one hundred. Had all the children in the population been able to participate, the total of 24, was still small and made identifying an effect difficult.

Another weakness of the study was the one time measurement of the quality of life variable. Quality of life is a complex concept influenced by many things including physical, psychological, emotional, developmental and social circumstances. To consider a one time measurement an actual reading on a child's quality of life is not an accurate assessment. The researcher included the quality of life concept in the study to procure the child's point of view regarding adherence. Quality of life is an important issue and may still affect adherence. Ideally however, quality of life should be compared within subjects, rather than between the groups (Adherence and Non-adherence), as was done in this study.

One limitation of the study was the length of the study period. The entire data collection period took 18 days from contact of the children's parents to the chart review. The children completed the questionnaire and the survey on the same day. With only one interaction with the child, it is difficult to identify variables that may have affected the quality of life measure. It also did not allow the child to become familiar with the researcher so that rapport could be established, possibly leading to a more honest exchange of information. It is difficult sometimes for children to open up to a stranger. For example, the interview was set up over the phone after the researcher and the parent discussed the study. Many times the child was not even aware why they were brought to the clinic or why there was someone in their home. They were given an explanation of the

study by the researcher before completing the questionnaire and the survey, as well as signing the consent form, but the element of surprise was still a factor.

Another limitation of the study was use of recorded data obtained from one source, medical records housed at NAS Jacksonville Clinic. Ideally, the children in the population used the Pediatric Clinic and NAS Jacksonville Hospital as their primary health care provider. At times, however, inability to obtain a timely appointment, traveling out of the area, or emergent situations, may have required the use of a hospital or health care provider besides NAS Jacksonville. In these instances, the medical resource utilization number may not reflect actual use of resources.

The Survey of Peak Flow Usage, used to measure the adherence of the children to the self-management plan is another weakness of the study. Adherence was determined through answers on the Survey. The children and the parents sometimes had difficulty understanding the terminology. For example not every child understood what the term "asthma control plan" meant, but when the researcher described the asthma control plan, they knew what it was. The survey may not have been measuring adherence if the child answered the questions as they thought they should have instead of how often they actually performed the tasks. Even if the child was accurate, there are many other factors that influence adherence in addition to whether the child uses his asthma control plan, daily use of peak flow monitoring and the tracking of the values.

Implications for Professional Practice

With health care reform and military downsizing, self-management education programs are a way to enlist the help of the patient and family in the management of the chronic disease, thereby increasing independence and decreasing dependence on the health

care provider. Asthma education programs in the military are in their infancy, with little documented findings on effectiveness of these programs. This study found the Asthma Education Program at NAS Jacksonville decreased emergency room visits and hospital admissions in all children who attended the Program. These findings provide the evidence to show support for military self-management programs for asthma as well as other chronic diseases.

Implications for Theory Building

The self-efficacy theory, self-management programs and an asthmatic child's quality of life are interrelated, and the main preface of this research. Self-efficacy holds that a child relies on two concepts to determine the extent that a self-management plan will be followed. The first of these is the belief that the child can perform the necessary tasks (self-efficacy expectancy), using the peak flow meter and taking the appropriate medications. Most children over the age of 5 years of age having the physical dexterity to perform these simple functions with some adult supervision. The second concept and probably the most important is the belief that something good will come of this self-management plan (outcome expectancy). A child's quality of life is one of these outcomes that needs to be addressed. The AQOL scores for both the Adherence and Non-adherence groups were higher when compared with other sample studies done using the CAQB including asthmatic and nonasthmatic groups. This paired with the fact that all children completed the Asthma Education Program, the group as a whole may have a higher self-efficacy or higher quality of life. Self-efficacy is the theory behind the amount of effort children are willing to put forth in maintaining the self-management plan. Self-efficacy is

an instrumental key between quality of life and maintenance of self-management plans and warrants further study.

Recommendations for Further Study

The development and implementation of this research proposal and study provided insight for future studies. Consideration of the following methodological changes should be considered.

Methodological Changes

There are several methodological changes that could be made in this study to possibly improve outcomes of the care of children with asthma and enhance measurement of the effect of the asthma education program. Repeated administrations of the quality of life questionnaire at selected intervals may enhance results. Ideally the first measure of quality of life should begin before the Education Program and continue over several months following the Program to evaluate its effects on the quality of life concept. The intermittent measurement of the quality of life may enable the researcher to control for those extraneous variables affecting quality of life that were a problem with the one-time measurement. The quality of life tool needs to be a valid and reliable instrument that is child-centered and developmentally appropriate, such as the Childhood Asthma Questionnaire. By using the same high quality tools in several different studies that include larger samples of all age groups, the results may be improved.

Using more precise criteria to measure adherence would further improve the study. Using data from the pharmacies, showing how often the child renewed medications may be one way to determine if they are indeed taking the medications as prescribed. Asking the child to keep an asthma diary or record of the actual peak flow monitor readings and

the list of medications they are taking on a daily basis may be another possibility for better defining adherence.

Recommendations

Because this was a descriptive study attempting to explore a possible relationship between adherence and quality of life, the researcher chose a small sample within a confined population. In further studies, increasing the sample size may improve the possibility of supporting the hypothesis and decrease the chance of a beta error. By performing a power analysis prior to the initiation of the investigation, the researcher may choose the best sample size for the desired effect. The researcher must keep in mind that quality of life measures are subjective and small differences may be meaningful and represent clinically significant if not statistically significant changes (French & Christie, 1995).

Because there can be differences in Quality of Life scores among the various categories of asthma (mild, moderate, and severe) (French & Christie, 1995), it may be helpful to distinguish the categories at the onset of the study. The subjects should be objectively categorized as mild, moderate, or severe using the specific criteria listed in the Guidelines (1991). The categorization should be completed by a health care provider who regularly follows the child for asthma symptoms. By identifying the category and sampling only moderate and severe asthmatic children, the results may be more meaningful.

One recommendation for a change in practice is for an initiation of an Asthma Education Program throughout the military that is standardized and based on the Guidelines (1991). With the development of an identical packet containing all necessary

forms and information, the child and the family are insured continuity of care even though they are traveling across the world to other military installations. This idea of continuity can be further realized with an Asthma Education Update for the Health Care Providers to ensure that children and parents are receiving the same information from all health care providers. The self-management plans will still be individualized, but that they will contain all the same pertinent information and everyone will be using the same terminology to address the different plan options. This study found a significant difference in behaviors before the Asthma Education Program and those after the Program, with even those children who did not adhere to the program reducing the use of medical resources. These conclusions certainly support the growth of additional Asthma Education Programs throughout the military health services system.

Summary

Asthmatic children showed a significant decrease in their use of emergency room visits and hospital admissions after completing the Asthma Education Program at NAS Jacksonville. The program is a worthwhile and cost-effective investment for both the military, the children and their families. Although quality of life and medical resource utilization were not affected by adherence to the Program, quality of life scores in both groups were high. Quality of life and self-efficacy are important in the asthmatic child's perceptions of how the disease is viewed and how it impacts the child's daily life. These interrelated concepts play a critical role in the success of the self-management plan. By understanding the relationship between a child's perceived quality of life and adherence to the self-management plan, health care providers may be able to develop a more holistic plan of care and controlling asthma symptoms.

Appendix A

Survey of Peak Flow Usage

1. Have you attended the Peak Flow Asthma Class? If yes where _____

YES

NO

- ## 2. Do you use your Peak Flow Monitor?

ALWAYS OFTEN SOMETIMES HARDLY EVER NEVER

- ### 3. Do you have an asthma control plan?

YES

NO

- 4. Do you use your asthma control plan?**

ALWAYS OFTEN SOMETIMES HARDLY EVER NEVER

5. Do you track for peak flows on a graph or asthma diary?

ALWAYS OFTEN SOMETIMES HARDLY EVER NEVER

6. How many days did you use your Peak Flow Monitor last week?

7 6 5 4 3 2 1 0

7. When was your last asthma attack?

8. What zone were you in today?

GREEN **YELLOW** **RED** **DON'T KNOW**

- How many days have you missed from school this year (Since September)?

Appendix B
Demographic Survey

1. Medical Record Number
2. Age
3. Gender
4. Race
5. Date or Age of First Asthma Symptoms
6. Date of Asthma Education Program
7. Number of Hospitalizations for Asthma (Before and After Class)
8. Number of Emergency Room Visits for Asthma (Before and After Class)
9. Number of Clinic Visits for Asthma (Before and After Class)
10. Date of Last Visit

Appendix C

Consent to Participate in Research

Impact of self-management program on perceived quality of life and resource utilization of asthmatic children ages 7 to 11

My name is Meg Carey, RN and I am a pediatric nurse practitioner student at the University of Florida, College of Nursing. I am currently conducting a research study to determine if use of an asthma control plan (set up by you and your doctor or nurse practitioner) influences your child's quality of life or affects the number of hospitalizations, emergency visits or asthma attacks. Quality of life is a term to describe how your child perceives his asthma and its relationship to his or her daily life.

Purpose of this study

The purpose of this study is to compare perceived quality of life, the number of emergency room visits, hospitalizations and asthma exacerbations in asthmatic children who follow a self-management plan and those who do not follow the plan. The aim of this study is to gain knowledge about the impact of certain asthma treatments on how a child views himself/herself and how asthma affects his or her daily life. The study will also compare the number of emergency room visits, hospital admissions, and clinic visits of children who follow a self-management plan and those who do not.

Criteria for entrance into study

1. Age 7 to 11 years who has completed an Asthma Education Program.
2. Child has an established asthma control plan.
3. Child and parent agree to complete a peak flow survey and quality of life questionnaire.

What will this mean for you?

If your child meets the above criteria, you and your child may choose to participate in this study. By choosing to participate, you will help in the advancement of a knowledge base regarding asthma and its treatment, and how it affects children's daily lives. Asthma is a chronic disease that affects all aspects of life and also influences how your child views himself/herself. It is my hope that we can learn as much as possible of the effects of asthma and its treatment in order to help children live their life to its fullest potential.

By entering into this study, you and your child will agree to the following:

I. Clinic Visit or Home Visit (approximately 30 minutes of your time).

- A. Complete a survey of peak flow usage.
- B. Complete a quality of life questionnaire.

II. Researcher will conduct a review of the medical record from the date of your child's first asthma symptoms to the present, comparing before and after the Asthma Education Program. The following information will be retrieved:

- A. Number and Type of Emergency Room Visits
- B. Number and Type of Hospital Admissions
- C. Number and Type of Clinic Visits
- D. Date of first asthma symptoms
- E. Date completed Asthma Education Program
- F. Medications and Dosages
- G. Race, Gender, Age

All of the above information will be coded and your child's name will not be used. All information will be kept under lock and key in a safe in the researcher's home.

At all times throughout the study I will be available to answer questions and handle any problems that arise, and please feel free to contact me. My digital beeper number is XXX-XXXX and my home phone number is XXX-XXXX.

If you have any questions about your rights as a research subject you should contact the Institutional Review Board at the University of Florida at 904-549-3136. Please refer to the study by the title above or Protocol UFJ96-119.

You may withdraw from the study at any time.

I, Meg Carey, will receive no direct benefit by your decision to take part in this research study.

Potential Benefits of the study

To further the health care knowledge regarding how asthma affects all areas of a child's life including how a child views himself in relationship to the disease.

Potential Risks of the study

No risks have been identified for this study.

Consent

_____, agrees to participate in this research study. The procedures have been explained and all questions have been answered.

Parent/Guardian

_____, agrees to participate in this research study. The procedures have been explained and all questions have been answered.

Participant _____ Date _____

I, Meg Carey, have fully explained the purpose, procedures, risks, benefits of the study to the above signed. I have to the best of my knowledge answered all questions and concerns.

Meg Carey, Graduate Student
University of Florida, College of Graduate Nursing

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BIOGRAPHICAL SKETCH

Margaret M. Carey was born in Philadelphia, PA. She graduated cum laude from Thomas Jefferson University, PA, with a Bachelor's of Science in Nursing in 1985. Her nursing experience includes staff and management positions in emergency departments in hospitals in Pennsylvania, New Jersey, Virginia and Florida. In 1991 she was commissioned into the United States Air Force and worked for 4 years on the Pediatric Ward at Keesler Medical Center, MS. It was at Keesler Medical Center she discovered her fondness for pediatrics and became an active advocate for children. She is a certified instructor for Pediatric Advanced Life Support and Advanced Cardiac Life Support. She is currently studying quality of life perceptions in children with asthma, the topic of her master's thesis. Upon graduation in 1997 from the University of Florida with a Master's of Science in Nursing, Captain Carey will accept a position as Pediatric Nurse Practitioner at Luke Air Force Base, AZ. She hopes to continue to be active in children's issues.